DOCUMENT RESUME

ED 408 118 RC 020 971

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TITLE	Support for Native Americans with Developmental Disabilities.
INSTITUTION	American Indian Health Service, Chicago, IL.
SPONS AGENCY	Illinois Planning Council on Developmental Disabilities, Springfield.
PUB DATE	26 Apr 96
NOTE	26p.
PUB TYPE	Information Analyses (070) -- Reports - Descriptive (141)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	Alcoholism; American Indian Culture; American Indian Education; Cultural Influences; *Delivery Systems; *Developmental Disabilities; Elementary Secondary Education; *Fetal Alcohol Syndrome; *Health Education; Poverty; Pregnancy; Prevention; Social Services; *Urban American Indians
IDENTIFIERS	*Access to Services; *Illinois; Native Americans

ABSTRACT

This report addresses the high incidence of fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE) among Native Americans and suggests that there is a lack of comprehensive effort to provide outreach services to the Native American population in Illinois. The report begins with an overview of American Indian history and the migration of Native Americans to the Chicago area since the 1950s. Although several organizations provide services specifically to American Indians, additional services are needed for this growing Chicago population. The leading cause of developmental disability in the Native American population are FAS and FAE. In addition, Native Americans have the highest prevalence of alcohol problems among all U.S. population groups. Illiteracy, lack of education, and a related lack of exposure to facts about drinking during pregnancy contribute to the high incidence of FAS and FAE among American Indians. Recent surveys of Illinois Native Americans revealed that most respondents were aware that it was detrimental to drink alcohol while pregnant, and 70 percent of respondents were concerned about a friend or relative who had used alcohol while pregnant. Disabled Native Americans encounter barriers to receiving appropriate services due to lack of knowledge among non-Native providers regarding the Native American community and its distinct cultural values, norms, and world views; economic barriers; and personal and familial barriers that prevent individuals from acknowledging problem drinking and the effects of substance abuse on children. The last section of the report includes recommendations for improving service delivery to disabled Native Americans, with the goal of empowering the Native American community toward independence and improving its linkage to non-Native service providers. (LP)

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Support for Native Americans With Developmental Disabilities

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Developed for and funded by The Illinois Planning Council on Developmental Disabilities

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SUPPORT FOR NATIVE AMERICANS WITH DEVELOPMENTAL DISABILITIES

APRIL 26, 1996

Authors: Wylie Goodman and Christine Rife

The preparation of this report and resource directory has been made possible by a grant from the Illinois Planning Council on Developmental Disabilities. The conclusions and recommendations provided in this report represent the views of these authors alone and are not necessarily the opinion of the granting organization. Copyright 1996

How mothers can drink and think it's all right,
While later their babies will have to
put up a hell of a fight
To do the things that normally everybody can do-
Like tell right from wrong,
concentrate and even sleep, too
So to all of you readers this
message does go:
Let your love for your children
really show;
And no matter what they do
don't give up the fight
Because in the long run you will
know that you have done
what is right.

Excerpt from *A Day in the Life* by Andrew (a child with Fetal Alcohol Syndrome)

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INTRODUCTION

Native Americans in the twentieth century inherit the legacy of over 200 years of cultural oppression, the effects of which are still felt by many today. Native Americans with disabilities face even more oppression. As people with disabilities, they can be stigmatized, labeled, and misunderstood by those in the mainstream. Within their own Native American communities, they can feel equally separate and alone; knowing they are different from others and yet, due to many communities' limited resources, having no opportunity to change their situation. When these same individuals have a disability due to maternal use of alcohol, their circumstances are that much more devastating. For, in reality, their disability was entirely preventable.

Such is the case for Native Americans born with Fetal Alcohol Syndrome and Fetal Alcohol Effects. Fetal Alcohol Syndrome is a congenital birth defect and the leading cause of preventable mental retardation in the Western world. Fetal Alcohol Syndrome occurs when a woman uses alcohol or illicit substances during pregnancy. The cost of FAS/FAE on families and society is enormous. In the state of Minnesota, for example, the Department of Alcohol and Substance Abuse estimates that the yearly cost of FAS/FAE is as high as $45,000,000. The personal costs, however, are immeasurable. As Michael Dorris, the author of the best-selling book on Fetal Alcohol Syndrome, *The Broken Cord*, aptly notes, "The hardest part of writing *The Broken Cord* was not being able to resolve it---for Adam, for me and the rest of the family." For FAS/FAE is not a condition people "grow out of." It is a condition that effects and disables people their entire lives.

While Fetal Alcohol Syndrome and Fetal Alcohol Effects know no racial or socioeconomic bounds, recent reports suggest that the condition is particularly high amongst Native Americans. A study by the National Institute on Alcohol Abuse and Alcoholism show that Native Americans have the highest prevalence of alcohol problems among all U.S. population groups. A report by the Urban Indian Council further suggests that Native American women between the ages of 15 and 34 have rates of cirrhosis death 37 times higher than that of White women the same age. Finally, a three year needs assessment conducted by the California Indian Maternal and Child Health Plan confirmed that FAS was a critical health concern in all Native American communities.

As a result of such findings, both Western and Native health care providers, educators, and social service agencies have begun seeking ways to lower the incidence and prevalence of FAS/FAE in Native American communities. One of the difficulties many encounter, however, is that Native American communities often have few resources internally to address this problem and yet at the same time are fearful of seeking services from non-Native providers due to decades of wrongful treatment by the non-Native community.

In the state of Illinois, however, there has been a noticeable lack of comprehensive attempts to outreach to the Native American community around the issue of FAS/FAE and developmental disabilities. One of the main reasons we speculate that this is so is due to the fact that Native Americans constitute

a relatively small percentage of the state's population. This, however, is about to change and has already begun to do so. In the last few years, more Native Americans are re-locating to urban centers such as Chicago and Joliet for work when they cannot find the same in rural communities in neighboring Great Lake states. As this trend continues, it will become increasingly important for state agencies to recognize that Native Americans are here to stay and that in order for them to become vital and viable members of the larger community, they must be engaged proactively and sensitively.

Which brings us back to the aims of this report: 1) to raise awareness among state agencies as to the presence of Native Americans in Illinois, 2) to examine the status of Native Americans with developmental disabilities in the state, particularly those with FAS/FAE, 3) to outline barriers which interfere with those persons receiving the services they need, and 4) to recommend strategies for overcoming these barriers. At the heart of this report is the belief that the currently available outreach, prevention, and intervention models directed towards people with developmental disabilities are ineffective for Native Americans because they fail to consider these individuals' unique cultural norms, worldviews, and values. This report will therefore recommend ways that currently available models can be modified in order to more adequately engage the Native American community. In conclusion, this report hopes to raise awareness among Native Americans and non-Native Americans alike that Fetal Alcohol Syndrome and Fetal Alcohol Effects constitute major health crises for the Native American community that, if not addressed swiftly, will significantly impair this community's ability to reach its full potential in years to come.

ONE
Who Are Native Americans?

There is no one correct term to describe the people who have been on this continent for thousands of years. Native American is currently the politically correct way to describe people who can trace their ancestors back to pre-Columbus America. The problem with the term Native American, however, is that people of European descent often consider themselves "native" Americans if they were born in this country. The term American Indian is also inaccurate since Christopher Columbus, thinking he was in India upon landing on this continent, incorrectly assumed that the people he encountered were therefore "Indians." Given that the statistics included in this report are from the U.S. Census Bureau--an agency that prefers the term Native American--this is the term that will be used most frequently in this report. Native Americans themselves tend to use the name they feel most comfortable with, often choosing to be known by their tribal affiliation rather than by either "Indian" or "Native American."

In trying to understand who Native Americans are, the first thing that must be understood is that their history with people of European descent has been violent, deadly and demoralizing. This history carries consequences into this century as many Native Americans tend to distrust government authority and intrusion to this day. Treaties, signed in the 1800's, between Native Peoples and the U.S. government promised Native Americans land of their own, health care, commodities and life without violence. These treaties were then repeatedly broken and are still being broken today. As a result of these broken treaties, Native people were forced to move to small tracts of land called Reservations where they faced hunger, poverty, and crime unlike anything they had experienced before contact with Europeans. Children were forcibly removed from families by the Bureau of Indian Affairs--the governmental agency established to reportedly look out for Native Americans' interest-and aided by state-funded social workers. Native American children were subsequently sent to boarding schools or adopted into White homes under the guise of its being in the child's best interest. The government also denied Native Americans' their right to religious freedom. Ceremonies such as the sweat lodge were outlawed and Native Americans were not allowed to practice their religion in ways that they had done for thousands of years. They were also forbidden to use their native languages.

Many of the legacies of this history of oppression remain with the Native American community today. Land once owned by Native Americans has been sold to Whites or simply given away leaving unresolved land disputes between Whites and Indians festering. The Black Hills battles over gold in recent years is only one of many examples in which Indians again lost out to White monetary interests. The Indians who remain on reservations are often forced to live in the face of great poverty and the crime that accompanies it. Native American languages have been lost forever, and those that have not are in danger of being so due to greatly diminished use. The history of oppression has also deeply upset the Native American family system. Only in the last twenty years, with the passage of the Indian Child Welfare Act, have Indian children removed from their homes been guaranteed placement within their own communities rather than with non-Native families. However, one of the more egregious vestiges of past injustices is that Native Americans continue to be governed by a two branches of government--the

United States government and the Bureau of Indian Affairs.

Another important aspect of the Native American community is its deep spirituality. Native Americans tend to see their spirituality as a way of life rather than as a distinct religion and, regardless of their denomination, participate in ceremonies that date back to pre-Columbus America. Ceremonies and rituals such as the sweat lodge -- the Native American equivalent of the modern sauna -- are considered to have special healing and purifying properties. Ceremonies differ from tribe to tribe, while sharing a common belief that ceremonies can be appropriate interventions for certain medical conditions. Many Native Americans also value the use of traditional "home remedies" to treat what some might consider modern illnesses. While Native Americans are in no means primitive, they cherish their unique religion and have gone to great lengths to preserve it in the face of modern encroachments.

For many non-Natives, however, Native spirituality was and continues to be enigmatic and misunderstood. Native Americans learn that respecting nature and living harmoniously with it are central goals of life while Europeans are typically taught that pursuing individual self-actualization is the highest form of achievement. While these differences may appear superficial, at one time they were the basis of an organized cultural genocide against Native Americans by non-Natives who feared and hated them simply for being different. Native American elders, children, and women were routinely shot, beaten, raped and murdered by non-Natives who saw them as savages rather than people. The holocaust against Native Americans was so devastating, that it actually wiped out whole bands of people who once inhabited this land.

In recent years, however, The Native American population has again been on the rise both locally and nationally. The reasons for the increase can be contributed to better Census Bureau methods of counting, higher life expectancies, increasing birth rates and a greater willingness of Native Americans to identify themselves as such. According to the U.S. Census Bureau, there were 1,959,000 Native Americans living in the U.S. in 1990. In the state of Illinois, the population of Native Americans is currently at 21,836 representing 133 tribes. The most largely represented Indian Nations in Illinois are the Cherokee, Chippewa (Ojibwe), Sioux, Iroquois, Canadian and Latin American, Blackfoot, Choctaw, Apache, Navajo, Menominee, Potawatomi and Winnebago. The large number of Ojibwe, Menominee, and Winnebago Indians in Chicago is probably due to the proximity of Wisconsin where most of these tribes were put on reservations. Cherokee is the most self-reported tribe in the state, but this is probably over-reported, because some Cherokee tribes do not require proof of blood quotient or lineage for enrollment, making it easy to claim heritage without actually presenting proof of ancestry. The Census bureau relies on self- identification without any proof of enrollment or blood quotient which is how many tribes recognize their own members. This leads to discrepancies between the Bureau of Indian Affairs, Tribal Governments and the Census Bureau numbers. It is important to note that the names Europeans chose to give a group of Indians was often generic. In actuality, a tribe is really made up of a number of small bands. For instance, the Chippewa have twelve federally recognized bands each with its own separate reservation. They include the Lac Courte Oreilles Band, Lac Du Flambeau Band, The Bad River Band, Red Lake Band, Red Cliff Band, The Sault Ste. Marie Tribe, Saginaw of Michigan, Sokoagon Chippewa Community of Mole Lake, Turtle Mountain Band, St. Croix Chippewa Indians, and Cass Lake Band. Non-Natives working with Native Americans need to be aware of both the differences and

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similarities between tribes so that treatment can be sensitively administered .

Native American migration to the city of Chicago began as early as the 1950's when the Bureau of Indian Affairs (BIA), to reduce its responsibilities to Indians on the reservations and to speed migration, began a Federal Relocation Program. The Program provided transportation to Chicago (among other large cities), one month's rent, and a living stipend. Most of the Native people who arrived were poorly educated and therefore poorly prepared to succeed in an urban setting. Again Indians encountered unemployment, poverty, a lack of health and social service care, and racism. Most of these early settlers moved into the Uptown and Lakeside neighborhoods on the North side of Chicago. Today, the largest number of Native Americans as well as Native American organizations in Chicago can still be found in the Uptown neighborhood. The neighborhood extends from Foster Avenue on the North to Montrose on the South and Ashland on the West to Lake Michigan to the East. Although the number of Native Americans in Chicago fluctuates quite a bit because many urban Native Americans regularly return to their reservations in times of economic stress or family or personal crisis, Native Americans are becoming a more permanent part of the Chicago community.

One of the major organizations serving the Native American community in this neighborhood is the American Indian Center which provides clothing and food to needy individuals and families and hosts a variety of social and cultural events for Native Americans. The Center has reportedly seen an increase in utilization in the past decade from Native Americans from other neighborhoods and even the suburbs who come there to attend events. Other organizations in the community include the American Indian Health Service (which provides medical, mental health, AIDS, and alcoholism treatment and prevention programs), Truman College (which houses The Institute for Native American Development and an alternative high school for Native American teenagers), the American Indian Economic Development Association (which offers services to American Indians trying to start businesses, buy homes, and lobby for changes in city government), St. Augustine's Center for the American Indian (which houses the Indian Child Welfare Program, an after-school program for children, a few social services, and a Drop-in center offering drug and alcohol counseling and respite for people who may have nowhere else to go).

Although the above description of sites may make it sound as if there are enough services for this community, there has in fact never been a systematic study of urban Native Americans and their healthcare and social service needs, this despite the fact that as of 1990 a little over half of the total Indian population lived in metropolitan areas. With this in mind, the following report seeks to clarify not only who Native Americans are, but what their current status is vis a vis healthcare, education, and social services. In order for this to be done, however, non-Natives need to be fully informed about this community and its cultural history. In conclusion, Native Americans constitute a diverse group of peoples whose values and worldviews differ not only from non-Natives but at times even from one other. Native Americans' culture is rooted in a respect for nature and a belief that living in harmony with nature is key to one's health and well-being. As more and more Native Americans, however, move to urban communities, they are in danger of losing touch with their original culture. For many Native Americans there seems to be a continual conflict between those values and the Western values that surround them each day. One of the greatest fallacies many non-Natives make is to assume that urban Native Americans

have abandoned their traditional values simply because they live in an urban setting. One of the goals of this project is in fact to reunite Native Americans with disabilities their own values and to integrate these as a vital part of treatment.

TWO
Factors Leading to Developmental Disabilities

Fetal Alcohol Syndrome is the leading cause of mental retardation nationwide. It is also the only causative factor in mental retardation which is one hundred percent preventable. FAS causes physical abnormalities of the face, joints and bones. It also causes growth deficiencies. Often this syndrome causes behavioral disorders, learning disabilities, communication impairments and socialization delays. The behavioral problems associated with Fetal Alcohol Syndrome are a result of damage to the central nervous system. Fetal Alcohol Syndrome is recognized as a disability by the Social Security Administration making it possible for people with FAS to receive medical and cash benefits related to their disability.

Incidences of Fetal Alcohol Effects have been estimated at three or four times the rate of Fetal Alcohol Syndrome. Fetal Alcohol Effects differ from Fetal Alcohol Syndrome in that there may be none of the physical characteristics common in FAS. People with Fetal Alcohol Effects typically exhibit the delays associated with damage to the central nervous system such as communication, behavioral, learning, and socialization deficiencies. However, since the physical characteristics are not evident, diagnosis of FAE is difficult and less likely to occur. While people with Fetal Alcohol Effects face many of the same challenges as do people with FAS, they are unfortunately not eligible for any benefits under Federal entitlement programs and are not recognized as having a medical condition.

The number one cause of developmental disability in the Native American community is Fetal Alcohol Syndrome and Fetal Alcohol Effects. Native Americans have the highest prevalence of alcohol problems among all U.S. population groups. Some experts even suggest that Native Americans run twice the risk than non-Indians do of becoming alcoholic. A study by the U.S. Department of Health and Human Services and the National Institute of Alcohol Abuse and Alcoholism concluded that Native American women are dying of cirrhosis at more than triple the rate of black women and at six times the rate of white women. The majority of researchers contend that sociocultural rather than biological or psychological factors underlie some Native American's abuse of alcohol.

However, for many Indians, alcohol offers a way of coping with problems that can often seem insurmountable. Poverty and unemployment, for example, have been frequently linked to alcohol abuse. Poverty puts more stress on individuals which can lead to them becoming depressed and turning to alcohol or other substances for emotional release. In the city of Chicago, twice as many Native Americans live in poverty do whites. According to the 1990 Census Bureau, 22.1% of Chicago's Native American population lived in poverty. The average family income for Native Americans was $11,251.00. And in 1990, 49.7% of all Native American families were headed by a single woman. Single women may face problems finding jobs that allow them to support their family as well as find affordable, safe day care for their children. Because of the difficulty paying for day care, some women find it easier to collect state or federal assistance rather than work. When this happens, they are not receiving work experience that would allow them to qualify for higher paying jobs. In addition, in 1990, 14.4% of the Native American population was unemployed and less then half of those who are employed worked less than a full 50

to 52 week year. Many Native American men work as truck drivers or janitors. Native American women held more positions as cashiers or secretaries. There was also a large number of Native Americans in positions of security guards, police, construction workers and school teachers. The Native American entrepreneur is also discriminated against by the city of Chicago for Native Americans are still not recognized as a minority group and therefore are ineligible for set aside programs and contracts from the city that might help them advance.

Illiteracy, a lack of education, and a related lack of exposure to facts about drinking during pregnancy are factors which also contribute to this disability's occurrence. Recently the Chicago public schools reported a 70% dropout rate for Native Americans. Almost half of the Indian population who are eligible for employment have not graduated high school. The Indian students who do not stay in school therefore do not participate in health education classes which discuss reproduction and stress the importance of dietary habits including the need to abstain from drugs and alcohol during pregnancy.

Poverty can also lead to disability when a family is unable to have their children's nutritional needs met. Families with little resources may purchase food they can afford not necessarily the food that is the most nutritious. Children are therefore not receiving all the vitamins and nutrients essential to their optimal growth and development. If the child is also cooking for the family then he or she will also lack knowledge regarding the requirements for a balanced meal. Poor nutrition can cause growth deficiencies, poor attention span and listlessness.

Because Native Americans often live in substandard housing, they are sometimes exposed to environmental poisons such as lead which can cause brain damage, growth retardation, liver damage and learning disabilities--problems commonly associated with Fetal Alcohol Syndrome and Fetal Alcohol Effects. The difference, however, between lead poisoning and Fetal Alcohol Syndrome is that an intervention strategy to detect the presence of lead in a child can be easily performed and treatments through diet or kelation therapy can fairly easily be implemented. The difference between lead poisoning and FAS/E too is that once a child has been assessed and shown to be affected by FAS/E there is no repairing the damage.

Living in a stressful high crime neighborhood is another factor which can lead to alcohol abuse and related disabilities. Families in high crime neighborhoods are often in jeopardy of becoming the victim of violent crime. In cases where a family member joins a gang, the individual can even become the perpetrator of crime. Gang violence has been linked to disabilities such as hearing loss, blindness, loss of limbs and partial or total paralysis.

Finally, a lack of chemically-free community role models hinders Native Americans from abstaining from alcohol during pregnancy. The stereotype of the "drunken Indian" is one many Native Americans know and unconsciously sense they are destined to enact. In families in which there is already a history of alcoholism, this is even more likely to be a resignedness about one's ability to fight the urge to drink.

In conclusion, with the predominance of high risk factors in the Native American community including a lack of adequate housing, nutrition, education, and employment, the need for support and services to Native Americans is tremendous.

THREE
Community Inquiry

Health care professionals serving the Native American community in Illinois estimate that as many as 50% of the population the state may have Fetal Alcohol Syndrome or Fetal Alcohol Effects. To establish the reliability of this estimate, a survey was conducted by this agency. To determine more precisely the specific numbers of individuals in the community with FAS/FAE, outreach, education, and training efforts continue.

Questionnaire 1.

Two questionnaires were distributed throughout the year to members of the Native American community. The first questionnaire sought to ascertain ways that the American Indian Health Service could assist the community with confronting disability-related issues. We first tried to gauge the community's knowledge of and attitudes towards Fetal Alcohol Syndrome and Fetal Alcohol Effects. We wanted to know where the community was getting information about this condition and what support systems we could implement in order to improve the likelihood that mother would be willing to seek treatment at our facility. A sample size of approximately 33 community members was surveyed. Subjects ranged in age from 15 to 50. As a result of this first survey, we learned that the majority of Native Americans in our relatively small sample, knew that it was detrimental to drink alcohol during pregnancy. However, 70% of our sample were concerned about a friend or relative of theirs who had used alcohol while pregnant in the last five years. Interestingly, many of our responders stated that they would be willing to talk to the mother about her behavior. This is extremely important in that it suggests that Native Americans need to be given the most complete and accurate information about this condition so that their own intervention efforts will be well-informed. There seemed to be a similar understanding regarding the importance of assessment for children exposed to alcohol or other substances in utero. Respondents stated overwhelmingly that the health clinic was the preferred agency they would turn to for help in this area. This finding pointed to a need for our clinic to train non-medical staff to do preliminary child assessments as well as to counsel parents as to service options.

Questionnaire 2.

The second questionnaire was administered at an FAS/FAE information booth at a community pow wow. Only women were asked to fill out the survey. Twenty-one women participated in the survey. The women ranged in age from 14 to 40. A majority of women stated that they learned about FAS from a variety of sources including the American Indian Health Service, the media, early childhood education classes, and their physicians. A few answered that they had just heard about FAS/FAE at the information booth. Eighty percent of those who completed the survey stated that while they themselves drank little or no alcohol, they still felt they should cut back on their drinking. One hypothesis was that many of our respondents may have had a drinking problem in the past but now abstain.

FOUR
Barriers to Service

There are many reasons why Native Americans with disabilities often do not access the services they both need and deserve. Some of the factors contributing to underutilization emanate from the Non-Native American community, others are interactional in nature--occurring between Native Americans and non-Native Americans--and still others are unique to the Native American community itself. Likewise, barriers can be systemic, familial and/or individual.

One of the most significant barriers for Native Americans with disabilities is a lack of knowledge on the part of Non-Native providers regarding the Native American community and its distinct cultural values, norms, and worldview. Misinformation and even prejudice against Native Americans has led some providers to erroneously conclude that Native Americans are beyond hope, that they will drink regardless of the dangers, and that they are therefore not worth prevention and/or intervention efforts. In fact, past providers' frustration with their inability to effect change among Native Americans, particularly with regard to substance use, is more likely due to their own lack of information regarding the Native American community's history with substance use and their failure to approach the community about this issue in a culturally sensitive manner.

Lack of knowledge has also led Non-Native providers to mistakenly interpret some Native American behaviors in ways that are detrimental to their receiving future services. For example, if families do not follow through on recommendations, non-Native providers may interpret this as disinterest on the family's part. In fact, providers may not understand that for many Native American families who live below the poverty line, seeking a costly assessment for what they see as a behavior problem is financially untenable. Similarly, something as relatively simple as scheduling an appointment can raise all sorts of cross-cultural misunderstandings. "Running on Indian Time" is a common expression referring to the practice of arriving or starting events late. While there is a general acceptance in the Native community that financial and transportation problems can make people late, the non-Native community may perceive arriving late to an appointment as rudeness or laziness.

In addition to cross-cultural barriers, there are also significant economic barriers to Native Americans' with disabilities getting appropriate services. At the most basic level, high rates of poverty in the Native American community mean that many individuals can not even afford the cost of the token they may need to get to a particular treatment site. Missing an appointment due to a lack of money is well-understood by Native Americans, but again, as noted above, may cause a Non-Native provider to see the client as irresponsible or non-compliant. Since services to people with disabilities are rarely concentrated in a single location, there is less likelihood that Native American clients will be able to follow through. Economic disadvantage also affects the

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quality of care people with FAS/FAE can receive. Many Native Americans, for example, rely on Medicaid for their basic health care. The services required to make a diagnosis of FAS/FAE, however, and to subsequently support an individual with FAS/FAE throughout their life, require more specialized diagnostic and treatment services than can often be provided by the public health system. Rarely does a family on Medicaid have the financial resources or the 'systemic savvy' to make contact with all the services and providers they may need. Furthermore, when less expensive services are sought, waiting times can be so prohibitive that many families may become disheartened and abandon getting their child or adolescent the services they need.

Finally, one of the most challenging dilemmas to providing services to Native American with disabilities are overcoming the internal-personal and familial barriers around acknowledging substance abuse and its effect on one's children. The stigma of having damaged one's own child is very strong and there is a great deal of guilt that goes along with learning of an FAS/FAE diagnosis. For many Native American woman, it might be preferable to believe her child is learning disabled or hyperactive rather than acknowledging that his or her difficulties are a result of FAS/FAE. Denial is a common response of Native American woman who are confronted by friends and family members about their drinking. Because there is such a strong belief in the Indian community that a woman's ability to give birth is a sacred bond, those who break the bond through substance abuse are highly shamed.

Households in which alcoholism has been present often have other impingements which increase the likelihood that a child with FAS/FAE in that household will fail to get the services they need. Poverty, domestic abuse, neglect and physical and sexual abuse, are often sad accompaniments to alcoholism. Thus in households where parents have a history of alcoholism, it is common that a child, even one affected by FAS/FAE, may assume pseudo-adult, caretaking responsibilities and thus never receive the services a "real" parent would be expected to investigate. In these same households in which parents have been unable to care for themselves, there is also little likelihood that these parents will even come close to meeting the extra attentional needs an FAS/FAE child requires. Thus the FAS/FAE child is never brought to a provider's attention or when he or she is, it is too late to make significant intervention.

In conclusion, Native Americans with disabilities encounter barriers to their receiving services on many different levels from cultural to personal. These barriers also interfere with all aspects of treatment. Native Americans rarely receive complete education about the dangers of substance use during pregnancy, are not interviewed adequately about their substance use to insure a safe birth, are not met with services during infancy when early intervention is most effective, and are not followed fully through the life cycle to insure that their children move towards successful independence. Thus Native American families and their FAS/FAE children spend their lives in a state of disinformation and ignorance--knowing neither the cause of their childrens' problems nor the solutions.

FIVE
Recommendations to Improve Service Delivery to Native Americans With Disabilities

The following recommendations regarding improving service delivery to Native Americans with disabilities have been developed with the Native American community's cultural history, norms, and values in mind. Recommendations seek to respectfully engage the Native American community at all levels of the decision-making process from fund allocation to outreach. The goals of the recommendations are to both empower the community towards greater independence in the long-term, while improving their linkage to non-Native providers who possess specialized expertise in the short-term.

In order to inform a discussion of how Illinois can best serve its Native American citizens, the recommendations utilize information gained through extensive discussions with representatives from Departments of Mental Health and Developmental Disabilities, Alcohol and Substance Abuse, and Department of Children and Family Services in neighboring states such as Minnesota and Wisconsin where Native Americans constitute a sizeable portion of the states' population. It is important to recognize that Illinois already has and will continue to see a rise in its own Native American population due to migration of tribes to urban centers like Chicago from more rural states where jobs are scarce. Neighboring states thus serve as an important model for how Illinois can modify its existing systems and/or developing new ones in order to effectively, economically, and sensitively accommodate the unique needs of Native Americans with disabilities.

While the recommendations below focus primarily on prevention and early intervention, these recommendations are easily modified to fit the needs of Native Americans with disabilities at every stage of the life cycle. One of the premises of this report, however, is that, as Michael Dorris, author of *The Broken Cord* stated, "The sole solution is prevention." When prevention is impossible, the next best solution is, as FAS specialists agree, early identification and intervention. It is also important to note that many of the recommendations provided here seek to address multiple rather than single barriers. For example, offering a state-sponsored "Health Care Pow Wow" at which Native American children can be screened for FAS/FAE in conjunction with their receiving more traditional health services serves to:

1) Provide services in a culturally sensitive manner
2) Improve links between Non-Native and Native clinicians
3) Reduce monetary expenditures for clients so that they don't need to travel to various sites, and,
4) Lessens the stigma parents of FAS/FAE children may feel regarding bringing their children in for evaluation.

Recommendations

1. SPONSOR A TOWN MEETING BETWEEN REPRESENTATIVES FROM STATE AGENCIES SERVING PEOPLE WITH DEVELOPMENTAL DISABILITIES IN ILLINOIS AND THE NATIVE AMERICAN COMMUNITY.

Native Americans often feel, and rightly so, that decisions regarding their lives and livelihoods have been made in the past without benefit of their consultation. Therefore, one of the first recommendations is that the major agencies serving people with developmental disabilities in Illinois hold a series of Town Meetings for Native Americans at which time questions can be put forth to the community regarding their needs and wants. By going directly to the community, as opposed to through community leaders, non-Native agencies will be in a better position to build trust and cooperation with future clients. While these agencies will need to consult with representatives from community-based Native American agencies in order to set-up such a meeting, the goal should be to get opinions from as representative a sample of the Native American population as possible. Providing a financial or food incentive to encourage attendance is suggested. In planning this event, non-Native agencies should be prepared that they may initially meet with mistrust from the Native American community. For this reason, we recommended that these agencies unite to sponsor a series of meetings rather than just one.

2. SPONSOR QUARTERLY "HEALTHCARE POWWOWS" IN THE NATIVE AMERICAN COMMUNITY AT WHICH TIME CHILDREN CAN BE SCREENED FOR FAS/FAE IN CONJUNCTION WITH THEIR RECEIVING OTHER HEALTH CARE SERVICES.

Because Native Americans often can not afford to get to the places where specialized evaluative and treatment services for disabilities are located, these services need to be offered: 1) in the Native American community itself or as close to the community as possible, 2) in as concentrated a period of time as possible, and 3) in conjunction with monetary incentives that encourage participation. An example of a unique and highly successful strategy used to outreach to the Native American community was one employed by the Department of Alcohol and Substance Abuse in the state of Washington. In that state where both poverty and rural isolation often interfere with Native Americans receiving services, the state has combined made health care service into a single day social event through the creation of "Health Care Pow Wows." A day-long event--held on a Saturday when more people could attend--could include screenings, immunization, school enrollment, and general health care services to a wide age range. Additionally, state funds could be allocated which would be used to provide food or household prizes to all those who attended. The prize would be distributed regardless of the child's FAS/FAE status. While clearly more extensive testing for disabilities would be required at a later time, the "HealthCare Powwow" would provide a good opportunity to distribute resource

directories and to network with parents and children who may wish to explore these services. The "Health Care Pow Wow" would also an opportunity to distribute preventive education literature.

3. GIVE NON-NATIVE HEALTHCARE PROVIDERS WHO POTENTIALLY SERVICE THE NATIVE COMMUNITY TRAINING AND RESOURCES SO THAT THEY CAN BETTER IDENTIFY NATIVE AMERICAN WOMEN WHO ARE USING ALCOHOL DURING PREGNANCY AND/OR THEIR FAS/FAE CHILDREN.

Native American women who use substances during pregnancy invariably come into contact with mainstream healthcare providers to handle many of their prenatal and delivery services. Thus one of the first places that changes need to occur are with the hospitals, doctors, and nurses who Native American women see under these circumstances. While many of these providers should already know about FAS/FAE, they may not have the knowledge, skills, and awareness to properly query a Native American woman about her substance use in order to get accurate information. Many Native American women are understandably fearful of disclosing their substance use due to a history of children being taken from the community for this very reason. Thus non-Native providers need to be educated by Native American experts and community representatives about the Native American community's perceptions of non-Native providers and what they may need to do differently when a Native American client comes to their office. Training doctors to ask even simple questions about tribe affiliation can increase a client's belief that her healthcare provider is empathic to her needs. Having a full understanding of the mistrust that exists between these two communities can make non-Native doctors and nurses both more sensitive and skilled when encountering a Native American client. Additionally, doctors need to receive training in how to reduce maternal guilt. Finkelstein et al.'s model of a program in which women are helped to recognize that they and their families are victims of alcoholism and that their drinking behaviors were not deliberately malicious is one that has proven effective.

Hospitals and clinics are also recommended to develop a liaison relationship between already existing Native American healthcare agencies and their own so that consultation can be sought for particularly difficult cases.

Finally, in addition to training non-Native providers on issues related to Native American history with the health care system and specific training regarding culturally sensitive interviewing, hospitals and related agencies involved in prenatal to pre-school care should be funded to purchase non-defensive screening measures such as the Chemical Use Questionnaire, T-ACE, and TWEAK which inquire into a women' alcohol use and which have all been recommended by Native American FAS specialists. Similarly, doctors would benefit from developing computerized tracking systems to do long-term follow-up on Native American children who are born with FAS/FAE symptoms. Given that so little research has been done with Native American Indians and disabilities, a tracking system would represent an important first step at quantitatively measuring the effects of FAS/FAE in this community.

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4. PROVIDE NON-HEALTH CARE PROVIDERS (EDUCATORS, CASE MANAGERS, HEADSTART FACILITATORS, AND DAY CARE PROVIDERS) WITH TRAINING ON BOTH FAS/FAE SCREENING AND NATIVE AMERICAN ISSUES.

Native American children come in contact with numerous other state-supported agencies such as schools, daycare facilities, and Headstart programs where there are unique opportunities to have providers administer simple pre-screening instruments regarding FAS/FAE as part of their regular intake procedures. For example, Headstart and pre-school programs could ask parents to fill out simple FAS/FAE pre-screening measures along with their completing other enrollment forms. Positive indicators on this screen could then lead to a referral of the family to a Native American agency for further testing. An FAS/FAE case management team could be established within the American Indian Health Service, for example, with the individuals on this team serving as community liaisons to these various agencies. The goal of the liaison team would be to ease the transition between referral and follow through.

5. ONCE FAS/FAE IS IDENTIFIED, PROVIDE NATIVE AMERICAN FAMILIES WITH FAS CASE MANAGERS.

Because families with FAS have such diverse needs from financial to psychological and social, and because many Native Americans may feel disempowered ad intimidated to proactively seek these services from non-native agencies, it is essential that native Americans and non-natives who are sensitive to native American issues be recruited, trained, ad hired to serve in the capacity of FAS case managers. These individual can arrange to be a consistent contact person through a child's life helping the family navigate unfamiliar systems as needed.

6. CREATE NATIVE AMERICAN-CENTERED BRANCH OFFICES OF PRE-EXISTING STATE AGENCIES IN NATIVE AMERICAN COMMUNITIES.

In the Uptown community, where many Native Americans in Chicago live, there currently exists only one Native American health provider agency. This agency subsists with only a single counselor, a part-time doctor, and a small handful of practicum-level nurse practitioners supervised by a licensed provider; I short, hardly enough people to adequately meet the needs of a community that totals approximately 33,000 statewide. It is therefore recommended that pre-existing state agencies such as DORS, DMHDD, DAFA, DSCC, and DOA open branch offices in the Native American community and/or recruit, train, and hire Native American individuals to serve in liaison positions in their main office with the stipulation that these individuals spend at least 30% of their time in community-based centers. By working within the context of pre-existing agencies, Native Americans who may lack management and administration skills have a better opportunity of gaining them than if they were forced to start up their own agencies without such skills. Outreach branch offices, however, will still need to work closely with pre-existing Native American agencies in order to insure that they are trusted and respected by community members.

7. CREATE A RESIDENTIAL TREATMENT FACILITY SPECIFICALLY FOR NATIVE AMERICANS. THE FACILITY WOULD BE LICENSED TO PROVIDE SERVICES FOR BOTH SUBSTANCE ABUSE TREATMENT AND FAS/FAE TREATMENT THROUGHOUT THE LIFE CYCLE.

In Minnesota and Wisconsin, mainstream healthcare providers are working more and more to incorporate traditional Native American practices into substance abuse treatment for Native American clients. Many studies suggest that programs such as Alcoholics Anonymous and Oxford House do not work well with Native Americans either because they are culturally inconsistent or because Native Americans in those programs experience isolation and racism from other clients. There is thus a need for the state of Illinois to set aside funding for the creation of a residential alcohol and rehabilitation site that is specifically for Native Americans and which incorporates Native American cultural practices as part of treatment. This facility, however, could also serve as a place where adolescents and adults with FAS/FAE who require more extensive care could reside and/or receive vocational training. Thunder Spirit Lodge and the Minnesota Indian Women's Resource Center could both serve as preliminary models for how treatment for Native American adults and children with Fetal Alcohol Syndrome could successfully be approached.

8. SPONSOR A "HEALTHY BABY MONTH" IN WHICH PROMOTIONAL MATERIAL DESIGNED SPECIFICALLY FOR NATIVE AMERICANS IS MADE AVAILABLE TO THE COMMUNITY.

In Wisconsin, the Department of Health and Social Services, the Office of Alcohol and other Drug Abuse, and the Wisconsin Council on Developmental Disabilities have teamed with other organizations, not-for-profits, and universities to sponsor a "Healthy Baby Month" every year during the month of March. The campaign distributes printed materials, posters, and audio-visual items to various health care and educational sites around the state. In addition, in preparation for the event, representatives from important community groups are invited to participate in the planning process. Sponsoring a similar event in Illinois and inviting Native Americans to participate would effectively spread the prevention and intervention word to Native American women who are in denial about their abuse. It could also help parents with newborns who are already affected link with appropriate agencies in order to initiate early intervention.

9. TRAIN FOSTER CARE PROVIDERS, ADOPTERS, AND FAMILIAL CUSTODIANS TO BE ALERT TO THE SIGNS OF FAS/FAE AND PROVIDE THEM WITH RESOURCE/REFERRAL DIRECTORIES.

RECRUIT AND TRAIN MORE NATIVE AMERICAN FOSTER CARE PROVIDERS.

In more recent years, Native American children are having more frequent contact with the Department of Children and Family Services. As a result, children with FAS/FAE are often being

placed in homes in which their caretakers may be unfamiliar with the diagnosis and its accompanying symptoms.

Relatedly, because both as children and adults, people with FAS/FAE are also more likely to be sexually and physically abused, DCFS case workers need to be made aware of the unique needs of children with FAS/FAE. In the case of Native American children, there are often a lack of Native American homes to which these children to be referred. Therefore, DCFS needs to make contact with the Native American community and to solicit participation from Native Americans to become foster parents. It will be necessary as well, in the case of FA/FAE children, to provide foster parents with more extensive training and services in order to prepare them for this parenting responsibility.

10. HAVE THE STATE OF ILLINOIS RECOGNIZE FETAL ALCOHOL EFFECTS AS A DISABILITY.

One of the greatest difficulties in terms of getting help to Native American children with FAS/FAE is having the resources in place to accurate identify this condition. In far too many cases, children with FAS/FAE are diagnosed as having ADD, ADHD, or a learning disability when in fact their inability to learn at their age-expected level is a by-product of maternal ingestion of alcohol. When this is the case, resources such as Social Security and vocational training need to be brought to bear to help these people through the life cycle. For Native Americans who already may have few resources, such services are essential to their survival. Currently, however, FAE is not recognized as a disability despite the fact that more children are born with FAE than full-blown FAS.

Related Recommendations

1. Invite Native American representatives to schools to provide in-services to educators about symptoms of FAS/FAE

2. Organize a network of service providers involved in genetics testings to provide newborn screenings through public health departments

3. Teach Public Defenders about FAS/E. Some Native Americans currently in Illinois penitentiaries may have committed crimes for which they are not entirely responsible due to their having FAS/FAE.

4. Establish a Native American desk within the Department of Developmental Disabilities. Arrange for the individual or individuals in this position to work closely with the Native American community on activities such as grant writing and fund raising to support their ability to better acquire outside funding to support future projects.

5. Insure that hospitals that get state funding have offered quarterly training to their ob/gyn and pediatric staff on working with Native Americans.

6. Provide opportunities for state-supported universities such as University of Illinois-Chicago to receive grant money for doing research related to urban Native Americans.

7. Use Illinois Arts Council funds to sponsor an arts festival featuring the work of Native American artists with disabilities such as William Ghost Dog.

8. Arrange to link Native American adolescents and adults with FAS/FAE into job training and placement with tribes in neighboring states so that they can be mentored in a culturally-supportive environment.

9. Recruit and train Native Americans to become licensed day care providers of FAS/FAE children.

10. Establish a "Native American" month in the state of Illinois. Use this event as an opportunity to promote awareness of Native American cultural traditions and strengths, while providing open forums for the Native American community to discuss common problems that go beyond tribal dissensions such as FAS/FAE.

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